PATIENT & CAREGIVER EDUCATION

Sapropterin

This information from UpToDate® Lexidrug™ explains what you need to know about this medication, including what it's used for, how to take it, its side effects, and when to call your healthcare provider.

Brand Names: US

Javygtor; Kuvan; Zelvysia

Brand Names: Canada

Kuvan; REDDY-Sapropterin

What is this drug used for?

- It is used to treat phenylketonuria (PKU).

What do I need to tell my doctor BEFORE I take this drug?

- If you are allergic to this drug; any part of this drug; or any other drugs, foods, or substances. Tell your doctor about the allergy and what signs you had.

This drug may interact with other drugs or health problems.

Tell your doctor and pharmacist about all of your drugs (prescription or OTC, natural products, vitamins) and health problems. You must check to make sure that it is safe for you to take this drug with all of your drugs and health problems. Do not start, stop, or change the dose of any drug without checking with your doctor.

What are some things I need to know or do while I take this drug?

- Tell all of your health care providers that you take this drug. This includes your doctors, nurses, pharmacists, and dentists.
- Have your blood work and other lab tests checked as you have been told by your doctor.
- Talk with your doctor if you have a fever or you are sick. Your dose may need to be changed.
- Follow the diet plan that your doctor told you about.
- This drug may not work for all people who use it. Talk with the doctor.
- Some people have had low blood phenylalanine levels with this drug. The chance is raised in children younger than 7 years of age. Blood levels that are too low for a long time may lead to very bad health problems. Talk with the doctor.
- Tell your doctor if you are pregnant, plan on getting pregnant, or are breast-feeding. You will need to talk about the benefits and risks to you and the baby.

What are some side effects that I need to call my doctor about right away?

WARNING/CAUTION: Even though it may be rare, some people may have very bad and sometimes deadly side effects when taking a drug. Tell your doctor or get medical help right away if you have any of the following signs or symptoms that may be related to a very bad side effect:

- Signs of an allergic reaction, like rash; hives; itching; red, swollen, blistered, or peeling skin with or without fever; wheezing; tightness in the chest or throat; trouble breathing, swallowing, or talking; unusual hoarseness; or swelling of the mouth, face, lips, tongue, or throat.
- Dizziness or passing out.
- Flushing.

- Cough.
- Shortness of breath.
- Fidgeting, moving around too much, or talking too much.
- Chest pain or pressure.
- Passing urine more often.
- Seizures.
- Swelling in the arms or legs.
- Feeling agitated.
- Stomach or bowel problems have happened with this drug. If not treated, these can lead to severe health problems like stomach or bowel ulcers or bleeding. Call your doctor right away if you have throat or stomach pain, severe upset stomach or throwing up, trouble swallowing, or decreased appetite. Call your doctor right away if you throw up blood; have throw up that looks like coffee grounds; or have black, tarry, or bloody stools.

What are some other side effects of this drug?

All drugs may cause side effects. However, many people have no side effects or only have minor side effects. Call your doctor or get medical help if any of these side effects or any other side effects bother you or do not go away:

- Headache.
- Diarrhea, upset stomach, or throwing up.
- Signs of a common cold.
- Joint pain.

These are not all of the side effects that may occur. If you have questions about side effects, call your doctor. Call your doctor for medical advice about side effects.

You may report side effects to your national health agency.

You may report side effects to the FDA at 1-800-332-1088. You may also report

side effects at https://www.fda.gov/medwatch.

How is this drug best taken?

Use this drug as ordered by your doctor. Read all information given to you. Follow all instructions closely.

Tablets:

- Take this drug at the same time of day.
- Take with a meal.
- This drug may be swallowed whole or mixed in water or apple juice.
- If mixing the tablets, mix with $^1/_2$ to 1 cup (4 to 8 ounces/120 to 240 mL) of water or apple juice. Drink within 15 minutes of mixing. It may take a few minutes for the tablets to dissolve. You may stir or crush the tablets to help the tablets dissolve faster. Rinse glass with more juice or water and drink.
- This drug may not dissolve all the way. You may see small pieces floating on the top of the water or apple juice. This is normal and safe to swallow.
- This drug may also be crushed and mixed in a small amount of soft food like applesauce or pudding.

Powder packet:

- Take this drug at the same time of day.
- Take with a meal.
- Do not open until you are ready to use.
- Be sure you know what the dose of this drug is. Be sure you know which types of packets to use to make up the dose. Talk to the doctor if you are not sure.
- Empty the powder into water or apple juice as you have been told. Mix well and be sure the powder dissolves fully. Drink within 30 minutes of mixing.
- The powder may also be mixed in a small amount of soft food like applesauce or pudding. Mix well and be sure the powder dissolves fully. Take within 30 minutes after mixing.

What do I do if I miss a dose?

- Take a missed dose as soon as you think about it on the same day you missed the dose.
- If you do not think about the missed dose until the next day, skip the missed dose and go back to your normal time.
- Do not take 2 doses on the same day.

How do I store and/or throw out this drug?

All products:

- Store at room temperature in a dry place. Do not store in a bathroom.
- Keep all drugs in a safe place. Keep all drugs out of the reach of children and pets.
- Throw away unused or expired drugs. Do not flush down a toilet or pour down a drain unless you are told to do so. Check with your pharmacist if you have questions about the best way to throw out drugs. There may be drug take-back programs in your area.

Tablets:

- Store in original container.
- Keep lid tightly closed.

General drug facts

- If your symptoms or health problems do not get better or if they become worse, call your doctor.
- Do not share your drugs with others and do not take anyone else's drugs.
- Some drugs may have another patient information leaflet. If you have any questions about this drug, please talk with your doctor, nurse, pharmacist, or other health care provider.
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doctor, nurse, pharmacist, or other health care provider.

- If you think there has been an overdose, call your poison control center or get medical care right away. Be ready to tell or show what was taken, how much, and when it happened.

Consumer Information Use and Disclaimer

This generalized information is a limited summary of diagnosis, treatment, and/or medication information. It is not meant to be comprehensive and should be used as a tool to help the user understand and/or assess potential diagnostic and treatment options. It does NOT include all information about conditions, treatments, medications, side effects, or risks that may apply to a specific patient. It is not intended to be medical advice or a substitute for the medical advice, diagnosis, or treatment of a health care provider based on the health care provider's examination and assessment of a patient's specific and unique circumstances. Patients must speak with a health care provider for complete information about their health, medical questions, and treatment options, including any risks or benefits regarding use of medications. This information does not endorse any treatments or medications as safe, effective, or approved for treating a specific patient. UpToDate, Inc. and its affiliates disclaim any warranty or liability relating to this information or the use thereof. The use of this information is governed by the Terms of Use, available at https://www.wolterskluwer.com/en/know/clinical-effectiveness-terms.

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If you have questions or concerns, contact your healthcare provider. A member of your care team will answer Monday through Friday from 9 a.m. to 5 p.m. Outside those hours, you can leave a message or talk with another MSK provider. There is always a doctor or nurse on call. If you're not sure how to reach your healthcare provider, call 212-639-2000.

For more resources, visit www.mskcc.org/pe to search our virtual library.

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